

FACULTY

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Sickle Cell Disease
Foundation of California

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California Department of
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Talking Drums Project
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Former Regional Pediatric
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Sickle Cell Disease
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Marsha Treadwell, PhD
Director - Talking Drums Project
Children's Hospital and
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Director-Patient Services Core
Northern California
Comprehensive Sickle Cell
Center

PLANNING COMMITTEE

Mary E. Brown
Mary Ferguson-Carro
Deborah Green
Eileen Murray
Marsha Treadwell, PhD
Kathleen Velazquez, MPH, MA
Karen Whitney, MS

SPONSORS/PARTNERS

Sickle Cell Disease Foundation of California (SCDFC)

The SCDFC is the first non-profit social service sickle cell disease organization established in the United States. Founded in 1957, the SCDFC provides direct programs and services to persons with sickle cell disease and their families.

Children's Hospital and Research Center at Oakland (CHRCO)

The Talking Drums Project is a sickle cell educational, outreach and patient service grant through CHRCO and the Northern California Comprehensive Sickle Cell Center (NCCSCC). The NCCSCC is the largest sickle cell program in the Western United States and is internationally renowned as at the forefront of sickle cell treatment and research.

California Department of Health Services, Genetic Disease Branch

California has the largest newborn screening program in the United States, testing all California newborns for PKU, Galactosemia, Primary Congenital Hypothyroidism and hemoglobin disorders such as Sickle Cell Anemia. The California Newborn Screening Program screens almost every baby born in the state, which accounts for one-eighth of the babies born in the entire U.S. Since the expanded program began in October 1980 over 12 million babies have been screened and more than 7,000 babies with a disorder have been identified.

Funding supported in part by Project #'s 2H46MC00243-02 & 2-H46MC00250-02-001 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health & Human Services.

Disclaimer: The Sickle Cell Disease Foundation of California, Children's Hospital and Research Center Oakland, the California Department of Health Services and the Maternal and Child Health Bureau, Health Resources and Service Administration, DHHS and their staffs are not responsible for injury or illness resulting from the use of medications or modalities discussed during this educational activity.



Sickle Cell Disease Foundation of California

6133 Bristol Parkway, #240

Culver City, CA 90230

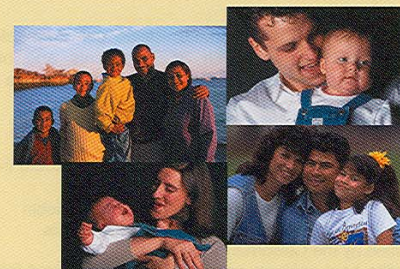
Phone: 310-693-0247

Fax: 310-693-0266

Email: info@scdfc.org

SICKLE CELL DISEASE

Services for Children
& Families in California



*An Educational Workshop for
Health Care Providers, Consumers
and the General Community*

Saturday, April 17, 2004

10:00 am—4:30 pm

Followed by a Wine & Cheese Reception

Wilshire Grand Hotel
930 Wilshire Boulevard
Los Angeles, California
Phone: (213) 688-7777 or (888) 773-2888

Workshop Sponsors:

*Sickle Cell Disease Foundation of California
Children's Hospital & Research Center at Oakland
California Department of Health Services,
Genetic Disease Branch*

WORKSHOP OVERVIEW

Program Description:

This program is designed to provide an overview of the California Newborn Screening (NBS) Program for sickle cell disease, health care resources and social service programs available to children and families with sickle cell disease (SCD) in California. Health education and sickle cell counseling resources for families with hemoglobin traits will also be provided.

Target Audience:

Physicians, nurses, social workers, sickle cell counselors, health educators, persons with SCD, parents and other individuals interested in the care of persons with sickle cell disease.

Objectives:

Upon completion of the program, the participants should be able to:

1. List at least three (3) clinically significant hemoglobin disorders and three (3) common hemoglobin traits identified by the California NBS Program.
2. Describe how newborn screening hemoglobin trait follow-up services are currently provided in California.
3. List at least two (2) common problems experienced by patients with SCD in emergency rooms and describe what measures are being developed by the Health Resources and Services Administration (HRSA) grantees in California to address these problems.
4. Describe at least one (1) service and how to access it, of each of the two California NBS sickle cell follow-up grants funded by the HRSA.
5. Describe at least one (1) potential impact of shrinking budgets on families with SCD.
6. List at least one (1) referral resource within their region (Northern, Southern or Central California) for families of children with SCD.

Registration:

\$35 per person if postmarked by April 3, 2004. Late registration (after April 3rd) is \$50 per person. A \$10 processing fee will be deducted for refunds before the April 3rd deadline. **NO REFUNDS WILL BE MADE AFTER April 4, 2004.**

Continuing Education Credit:

Accreditation: This activity is offered by Children's Hospital and Research Center at Oakland, a CME provider. Physicians attending this course may report up to 5.5 hours of Category 1 credit towards the California Medical Association's Certificate in Continuing Medical Education and the American Medical Association's Physician's Recognition Award. A \$25 processing fee will be charged at the workshop.

Nurses: 5.5 contact hours provided by the California Department of Health Services, Genetic Disease Branch, California BRN Provider Number 12857.

LCSW's: The Sickle Cell Disease Foundation of California is accredited by the California Board of Behavioral Sciences. Course meets the qualifications for 5.5 hours of continuing education credit for LCSW's as required by the California Board of Behavioral Sciences. Provider number PCE 2910.



PROGRAM

- 10:00 am Introductions, Meeting Overview
Mary E. Brown
Marsha Treadwell, Ph.D.
- 10:15 a.m. California Newborn Screening Program
George Cunningham, MD, MPH
- 10:45 a.m. Sickle Cell Disease & NBS Project
Judy Hagopian, MSW
- BabySteps: SCD Follow-up Program for parents of infants with Sickle Cell Disease
Deborah Green
- Talking Drums II: Using the power of communication to improve care provided to individuals affected by SCD and trait
Marsha Treadwell, PhD
- 11:15 a.m. BREAK
- 11:30 a.m. Improving Care of Individuals with SCD in the Emergency Department
Keith Quirolo, MD
- Patient Experiences in the Emergency Dept.
Jane Gardere,
Wanda Kenlow-Thomas
- 12:30 p.m. LUNCH (buffet)
- 1:00 p.m. SCD Care in the Face of Shrinking Budgets
Laurie Soman, MSW
Michael LeNoir, MD
- 1:45 p.m. BREAK
- 2:00 p.m. Breakout Session I
a) Collaborations that Work—No. California
b) Collaborations that Work—So. California
c) Educating Children with SCD about their disease—how, when & where
Charlotte Hoof-Dixon, RN
- 3:00 p.m. Breakout Session II
a) Thinking Outside of the Box—The Potential for New Partnerships
Laurie Soman, MSW
b) Effective Communication between Patients and Emergency Department Providers
Poppy Dere, MA
c) Culturally Sensitive Care
Mary Ferguson-Carro
- 4:00 p.m. Wrap Up / Next Steps
- 4:30 p.m. Wine & Cheese Reception

REGISTRATION FORM

Registration form & \$35 registration fee postmarked by April 3, 2004 (\$50 after April 4th)

Name: _____

Title: _____

☐ MD/DO ☐ NP/RN ☐ PA ☐ PT

☐ Social Worker ☐ Sickle Cell Counselor

☐ Other: _____

☐ I will be reporting CMEs or CEUs.

Agency: _____

Address: _____

City: _____

State: _____ Zip: _____

Phone: () _____

Fax: () _____

Email: _____

Payment Method:

☐ Check ***Please make checks payable to: SCDFC***

☐ Visa ☐ MasterCard ☐ AMEX

Card # _____

Exp Date: ____ / ____ Amount \$ _____.00

Name on Card: _____

Signature: _____

Completed form and registration fee of **\$35** postmarked by **April 3, 2004** (\$50 after April 3, 2004) should be mailed to:

Sickle Cell Disease Foundation of California
6133 Bristol Parkway, #240
Culver City, CA 90230

Phone: 310-693-0247

Fax: 310-693-0266

Email: info@scdfc.org